

Colorado Home and Community Based Services (HCBS) Settings Non-Residential Stakeholder Workgroup Meeting #5 March 10, 2016

The intent of these workgroups is to problem solve and gather ideas surrounding implementation of the Home and Community Based Services (HCBS) Settings Rule. This group is moderated by The Lewin Group at the request of The Colorado Department Health Care Policy and Financing (the Department). The intent of these notes is to capture the exact nature of the comments of the workgroup participants and is not representative of policy decisions or the Department's stance on implementation. Notes from workgroups to date can be found at:

www.colorado.gov/hcpf/home-and-community-based-services-settings-final-rule

I. Workgroup Participants

Stakeholders Present:

Christina Neill Bowen, Lewin Group
(facilitator)
Kristen Rice, Lewin Group (note-taker)
Adam Tucker, HCPF
Caitlin Phillips, HCPF
Deana Conaty, Brain Care
Karen Lillie, Pueblo Diversified Industries
Celeste Ewert, Envision
Jan Irvin, Foothills Gateway
Julie Bansch-Wickert, Disability Law
Michelle King, King Adult Day Program
Tamara Drumright, DDRC
Leah McMahon, Colorado Access
Gerrie Frohne, PADCO

Barb Wilkins-Crowder, ACMI
Candie Dalton, Accent on Independence
Mary Jo Rymer, ARC of Colorado

Stakeholders Absent:

Steven Shauchnessy
Cindy Reynolds, Joan Wilson, Mountain
Community Pathways
Cassidy Dellemonache, PASCO
Danny Holzer, Jeffco OLTC
Tamara French, Discover Good Will
Jenny Nate, Rocky Mountain Health Plans
Tia Saucedo, Leading Age

II. Introduction

Christina Neill Bowen welcomed the stakeholder group attendees to the final stakeholder non-residential meeting and thanked them for their participation since November. Christina then followed with a roll call of attendees and asked each person to share their name, organization, and one thing they are hoping will come out of the compendium.

- The Colorado Department Health Care Policy and Financing (the Department) hopes that the product produced will allow providers to explore the new settings rule and find innovative ways to address it before the rules and licensure change, especially around

community integration. Hopefully it will provide information about providing services and supporting individuals in living a life of their choice.

Participants shared the following hopes:

- This product should give clarity for the adult day regulations that are going to be adjusted for the final rule.
- I hope it will give providers a tool kit to help them be able to implement the final rule change.
- I hope that the system will allow for a full spectrum of choices and respect a person's ability to choose a life that they want.
- I hope we end up with a process and system that is wholly focused on person centered care.
- New and creative ways to offer choice and activities to people.
- A vision and concrete tools that actually get supported by the system in all ways.
- Something that allows people to have their own individual design in how to live their life each day.
- Focus on a full range of choices with the recognition that there are individuals with significant needs.
- Recognition of the tensions and constraints as well as the dreams of hopes.
- Concrete tools. While we are supporting choice, we are given the empowerment to do that by the state, case managers and regulators.

Christina thanked them for submitting their written comments on a few different documents. Caitlin stated the Department is in the process of re-working their Statewide Transition Plan (STP) and assessments concurrently with the groups. The next public comment period is going to be May 27th on the transition plan. The changes to the regulations will be also public noticed in a crosswalk document. During the last comment period the Department received only one comment, so the Department encouraged the group to comment and spread the word for this next round of public comment. The month of June will be time to post things publicly. The Department will be posting an executive summary of the STP that will make it easier to follow. The STP is a very content heavy document. Hopefully your experience in this workgroup will make it easier to fully understand the transition plan and the crosswalk that will be posted with it.

Christina showed the Colorado HCBS Settings Rule website www.colorado.gov/hcpf/home-and-community-based-services-settings-final-rule where participants can keep updated on the rulings and meeting notes going forward. The goal for this call is to share the draft compilation of best practices and hear from the workgroup. This will be in addition to the written comments that have already been submitted.

Christina reviewed the purpose of the workgroup, the working group agreements, and the sections of the compendium. They include an introduction, methodology and the stakeholder selection process, a section on broad promising practices that might apply to all settings, specific promising practices that would apply to specific settings, and a conclusion. We want to go through the broad themes that have emerged. She opened the line for suggestions or reactions on how the compendium is organized and how the stakeholders were represented.

- The general feedback was that the structure looks good, no missing pieces, seems to flow well.

III. Broad Promising Practices

Christina asked if there were any major areas of focus today or reactions to peers' comments from the last call. The group had none. Christina then showed the broad promising practices on the screen and for each one asked if the group wanted to provide additional content.

Viewing person centeredness as a philosophy and process vs as a one-time event

Christina asked if workgroup members had any additions or considerations about this practice.

- It is important to emphasize that true person centeredness benefits everyone involved. You don't want to get stuck in looking at just the one person. The circle of friends (cited as an example) worked well for one person, but didn't benefit everyone. We need tools or examples of how it can work for everyone so that it becomes something that all staff use for everyone that they support. I don't know if everyone on the line has been trained in person centeredness. We train all of our staff. Some of the things that really work are starting with a one page profile for every person supported. It is an interview with them and their family and those that work with them the most. It provides information on how to best support the person and it follows them through transitions (e.g., school, hospital, etc.). It has their likes and dislikes. We also have staff complete them on themselves. It helps match staff with the people supported. It's a great place to start. You can set little milestones—10 people this month, 10 the next, and then everyone has one in 6 months. (This was from Celeste Ewert with Envision)
- At Foothills Gateway we do the same for staff and individuals supported—the one page profile.

Making the most of care support meetings

Christina: This theme emerged in our previous discussions. It entails doing pre-work to identify things important to and important for the individual and getting the right folks around the table

- No additional feedback.

Expanding on the process of facilitating of informed choice to promote a common understanding.

- My knowledge is from my experience in the IDD world, so it may or may not apply to others. Informed choice has to be getting a sense of a person's preference. If people have done certain things that they have experience with all their life, for example they are coming out of school and that's their experience, or a day program, informed choice will be a very challenging and expensive process. I don't feel at this stage that any of the Department's work on the settings rule should be focused on dollars. We made that agreement with the Community Living Advisory Group (CLAG). You don't get concerned about the money, because then that's all you are talking about. It won't be easy or cheap. Some of the things that one can do for someone who has never done anything but a day program is to present the person with information in the form of pictures or videos and watch for any kind of positive reaction. If someone is looking at a short video that also includes themselves or someone they know, but the video is of a different location. For example, they see people taking care of horses and they look bored, but then they look interested at a video of dogs.
- Christina showed the draft decision flow. The residential group brought up that in the second box, they wanted observation added as well for people that don't communicate with words. What do you think about that?
 - If the question is "can informed choice be offered to people through typical or standard method?" The answer is no. Informed choice doesn't mean that you sit down with a check list and say to someone "what do you want to do?" and expect them to tell you or not. There must be multiple venues for seeking those choices from people. Doing that doesn't have to over complicate the process. There are relatively simple ways. I'm thinking broader, not just IDD. Choices that are offered are often not person centered or are not offered with real genuine information. If I had to choose between being alone and falling down versus going into a nursing home, then I guess I'd go to the nursing home because I don't want to die alone at home. In the broad population, the settings rule and kind of changes we want to see may not directly cost more money.
 - That is wonderful. I think what she said is perfect
 - I agree with the tension that Mary Jo set up. Sometimes we don't have a good option and that really isn't choice.
- Christina: The residential group thought the diagram should be circular rather than linear. What do you think?
 - Yes, I think it is more of a process, not a one-time thing. It should be more like a triangle, spiral, or circle.
 - It isn't a linear process. Observation doesn't work as well in the community setting. Perhaps instead of observation, we add time for consideration or

reflection. This is because we don't have daily observation in the community. I'm coming from single entry point where we don't have daily services or contact.

- I agree with a circular observation. A lot of the choice is front loaded on Medicaid case managers. They have a lot people on their case load. They need to know what options are out there. They are given a list, but not really given recommendations. We need to maintain that they are soliciting for just one program and clients don't have to stay with that choice. Not every program is that way.
- Regarding case management roles, the conflict free case management meetings going on talk a lot about expanding the numbers of case managers, the trainings, the types, even having family members have case management authority. We are in a very dynamic time with all of these things going on at the same time. Maybe right now we have a limitation on case management caseloads, but they also talked about niche case management for folks that have a specific kind of need. We don't want to limit things by the fact that case managers may not have time or ability to explore options.
- I echo that. The concept of niche case management is interesting. I'll give you an example from a friend who won't mind. There were twin young men who had cerebral palsy, one did not use words to communicate. As they became adults, the process to coordinate took weeks of time to keep them from being hospitalized. Their mother knew the system like the back of her hand. Case management has to be different in these cases. This has to be built into the system for case managers who have expertise across the systems and understand all sides and can help pull all of these thing together. Costs may be considerable, but there are some in LTSS that don't want or need a lot of case management. The system is designed as one size fits all, but this doesn't work. I'm going to sound like Bernie Sanders. We need to redistribute resources so that people get what they need—not more than they need and certainly not less.
- Christina: Is this a valuable tool to put in our final report? How do we want to frame it?
 - Yes, I think it is. If we do some tweaking and add in the observation or response piece and make it more of a process rather than linear, then yes.
 - Others agreed.
- Christina: Are there any other things out there about informed choice? No response

Working within the current budget structures and reimbursement rates, increasing opportunities for one-on-one support, developing natural supports, promoting supported employment, and public education on community inclusion.

- I think working within current budget structures—I would like to see it off the table. Replace it with something like we don't know what the world is going to be like in 2019 and I just think that the word "current" may not really apply. Instead of working in the current structures, there will be a need to consider sustainability. Something very vague like consideration of sustainability. Keep it very vague so people can't say "we can't afford that."
- I agree. Working within current structures and rates is not really promising. The fee for service rate is often too low to provide staff for people with LTSS needs. Sustainability is important, but it isn't a promising practice to say we're stuck in the rates that we have. We need to be able to be flexible and blend funding from a variety of sources. What did the residential group say?
- Christina: They didn't comment much on this. Maybe this doesn't fit in promising practices, but there is the theme of not having more funding coming down, so maybe we focus on what we can do with existing dollars and flexibility with funding.
- Caitlin (the Department): I love the idea of changing the language and being more vague and using the word sustainability. As far as the flexibility, this is a big part of a lot of initiatives to make services more widely available. Waiver simplification for instance. We acknowledge that the existing rate structure is not great. These initiatives are trying to remedy that while keeping in mind the fiscal limitations. We hear you.
- Christina: It makes me think that we should summarize those initiatives in the background piece of the compendium
- Developing natural supports should be "developing and sustaining." We may need support to do that. If we can get allies (the boy scouts for example), the assumption that it just happens on its own is erroneous. We need to develop those relationships and they need to be sustained. The monitoring and follow up on those relationships are working in the best way for both people. On public education, there is something about it that bothers me. The way the community comes to accept people is by being around them. A structured educational approach doesn't make sense to me.
 - That makes sense to me. I remember conversations around this—using media to present vignettes on community inclusion. Educating chambers of commerce or professional business groups. That made sense because it covered the necessity of education on people with disabilities and older adults on their gifts and contributions.
 - Right, there is a need for that.

- Particularly around employment and looking past disabilities is good public outreach to do.

Facilitating an on-going dialogue about rights, forum to discuss rights issues, working with guardians and protecting participant rights, and respecting rights while managing risk/liability and individual decision making.

Christina: Candie, do you have comments about the human rights committee?

- It concerns me a little bit. The Intellectual and Developmental Disabilities (I/DD) services have a structure for the committee, but I'm not sure that other populations do. There are a lot of stakeholders that have concerns about the committee—how it is structured, the power that they have. So taking an already concerning committee and moving to other populations might not be in the best interest of the people that we serve. One thing that human rights committees look at is the use of psychotropic medications. Some just look for informed consent and that the administrative processes have been met. Others really look at what the psychiatrist has recommended and make judgements about it. Most think this is outside of their purview. To have a committee follow people that are already being followed closely would be problematic.
 - Around the mental health waiver—I take your point. When I think about doing this in the mental health waiver, I'm thinking about folks that are not on medications and making choices that put them at risk. To have some sort of review panel for providers and case manager to dialogue with. We don't really have anything in the community setting for that.
 - I hear that loud and clear. That illustrates that maybe there is something needed, but I don't know that current structure of the human rights committee is set up for that.
 - That is a really good point. The human rights committee established for the IDD population was to have someone review any kind of rights restrictions. And now medications are now part of the equation. I would suggest a broad recommendation that there needs to be some type of oversight and monitoring regarding rights and restrictions for people with LTSS in the community.
 - I might just use dialogue or feedback or consultation rather than oversight or monitoring.
 - I like consultation.
- Christina: What tools can we put out there for providers and advocates? I'm wondering how to frame this? Are we talking formalized or a way for providers to just reach out?

Adam (the Department): Going back to natural supports. It is really something that is very important to the new settings rule. I want us to really be thinking that these should be

friendships and sometimes mentorships. Don't over think it. Do your due diligence with background checks. When a new friend pops up, I vet them. I'll bring in my wife to see what she thinks. Are there red flags popping up? We are concerned about liability for the people we serve, but we don't do that in our personal lives. Think about how we manage our friends and then support people in how they do that. I also have been looking for some tools on how to support people in gaining natural supports. If anyone is doing this in person centered counseling or anywhere else, if you could share that with me, it would be really helpful. I'll share that with others.

- In the fourth bullet, it totally gets covered there (working with guardians and all). That is a really good statement about respecting rights while managing liability. I think developing and sustaining natural supports is fine as it is. Between both of those you have the Departments input.

Christina, Is there anything else that we need to touch on?

- We didn't get to finish that last piece about rights. I would encourage us to think about something a little more formal, maybe an expansion on the ombudsmen program. We don't need rules about how they reach out, but there should be something in place.
- Isn't that covered under case management?
- I'm not sure that it is for all populations.
- Christina: Because this report is going to be more practical and not make recommendations, are there things we can encourage folks to do with the compendium?
 - You could cite related examples, such as the human rights committee in the I/DD population and also in the PACE program there is a requirement around interdisciplinary teams that include everyone from the podiatrist to the van driver. There might be a way to reference that as an example.
 - I appreciate what you are saying that we aren't making recommendations. Maybe an encouragement not to hesitate to reach out for professional consultation, and then cite examples.
 - The "forum to discuss rights issue" what Barbara just described fits there.
 - Yes, lets round out that phrase
 - Christina: We had the human rights committee under that too. That's where that came from.

Christina: There is a training coming up around working with guardians. Our next webinar on March 31st is about guardianship and alternatives to guardianship, emerging best practices and how guardianship interacts with the new HCBS settings rule. It will also cover how we can we support guardians and individuals who have guardians.

- Would you send that to the whole group on today's meeting?
- Adam (the Department): Yes, we will make sure. If you are encountering folks who aren't getting these communications, please help us connect with them.

IV. Leaving in Action

Christina encouraged members to share a promising practice and asked if anything jumps out that we should absolutely include? [No response.] You can also email us afterwards. We may be contacting some of you as we build the compendium.

Christina: Is there anything else on your minds as we wrap this up?

- Is it okay if we invite promising practices from people not on this group?
 - Yes.
 - Adam (the Department): If you have others we definitely we want to hear from them, but please channel them through this group. We don't want to make sure the purpose of the group is clear.
- What will the process be to get this out to people?
 - We will put together the report and then the Department will make sure it is on the website. That is where this will live. We will also send out communication briefs and do a blitz on getting the word out about how they can access the document. We also hope that everyone in the work groups will do a little bit too—talk about it in meetings, with people you work with, and other providers. Mention that it is out there.
- The promising practices that you get from reliable entities; will those be included in the format that you described and actually out there as examples?
 - Yes, that is the intention. It will have to go through clearance. We want it as concrete as possible with a person to contact and a place to go for more information.

Christina and the Department representatives thanked participants for their participation.